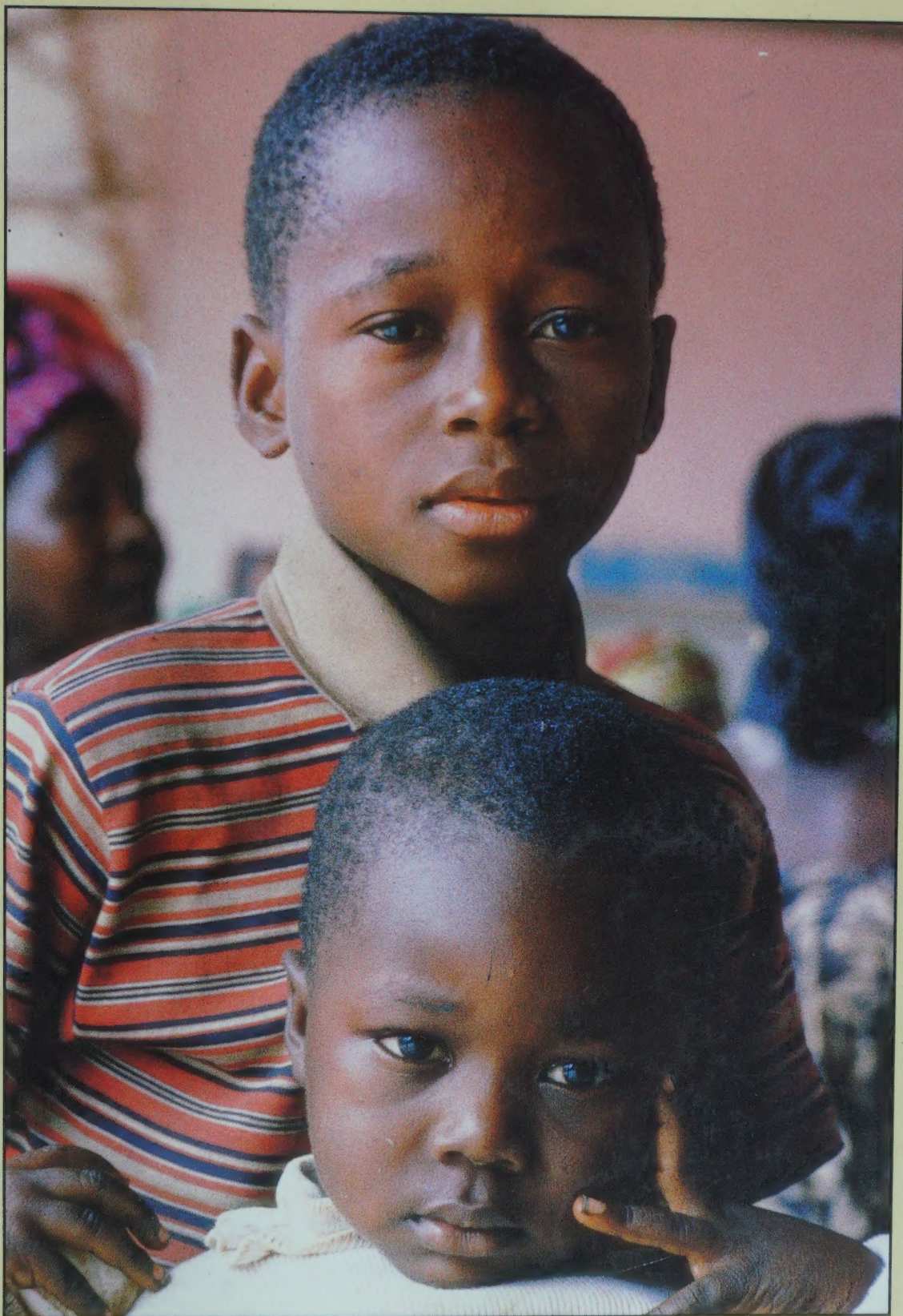


# CHILDREN AND AIDS: AN IMPENDING CALAMITY

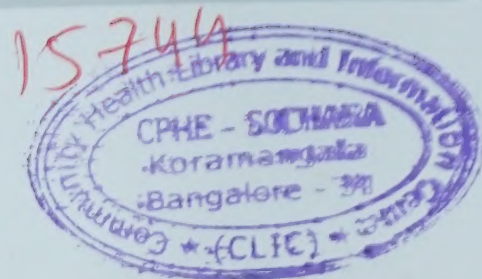
The growing impact of HIV infection on women, children,  
and family life in the developing world.



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# Children and AIDS:

## An impending calamity

A little girl, her face puckered and tearful, sits in front of a bowl of food. Today is one of her bad days, she is uncomfortable, unwell. Only with coaxing will she eat anything at all, and the fruitlessness of months of coaxing shows in her small size and frailty, arms and legs of a six-month old in an 18-month-old body. An "auntie", mother of another child, rocks her on her knee and tries to tease half a spoonful between her lips.

This is an AIDS child in a rural hospital in Africa. Her mother died soon after she was born. The father brought money and asked the staff to mind his daughter for a while because he no longer had a home where he could take her. From time to time he came on the bus and played with her. But she was always sickly, never did well. After a year the nursing staff drew the inevitable conclusion. Since the father was told that his daughter is suffering from human immunodeficiency virus and AIDS, he has not been back to visit. Perhaps he too is dying.

This child is one of thousands of such cases. Typically in East and Central Africa, one in ten of those with AIDS are children under five. With increasing numbers of women infected, and between one-quarter and one-half of infected pregnant women passing on the infection to their newborn, the thousands of cases are growing. Analysts describe in pessimistic tones the impact of AIDS on the child mortality statistics in the developing world, and the prospective reversal of recent progress in child survival in seriously affected areas. Such discussion does little to convey the tragedy of AIDS in the cradle of a mother's arms.

This is not a disease like other diseases. There is no win-or-lose struggle with a life-threatening infection. For the mother – if she is still alive herself – there is no one agonizing

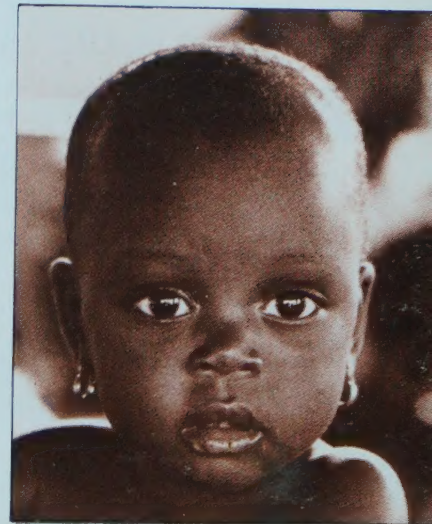
crisis watched over from beside the cot, followed by either the pain of losing her child or the promise of recovery to full health and well-being. The HIV-infected child is lost from birth, comes into the world with an agent hidden in the blood waiting to thwart the body's every attempt to construct routine defences against disease invasion.

The ramifications of each tragic case are multiple. First there is the mother, who is herself HIV-infected and must deal with her own impending death as well as her baby's. Then there is her husband who is very likely to be infected, and other partners who form potential links in the chain of transmission. There are the child's brothers and sisters, soon to be orphaned. Finally, there are the grandparents, expecting at their age and degree of infirmity to be sustained by grown sons and daughters, finding instead that their home is a refuge for children from a series of devastated households and that somehow they will have to provide.

In some pockets of Africa, AIDS has already infected between one-fifth and one-quarter of otherwise healthy adults of child-bearing age. This is a calamity whose dimensions are scarcely comprehensible, and it shows all the signs of spreading elsewhere in the developing world. Many of those who live with it, in their own bodies and minds or in those of their relatives, in medical and children's wards, in patients' homes and in the community, endure it with courage and numb resignation. As in war, dying has become a commonplace; the irreparable tears in the family and social fabric require that the unacceptable be accepted, the unbearable be borne.

For those fighting AIDS in Africa, whether on the frontline or at one stage removed, the battle is hard. For the face of AIDS in the community is not a phenomenon full of visible

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**What is AIDS?** AIDS – Acquired Immunodeficiency Syndrome – is caused by a virus known as HIV, human immunodeficiency virus. HIV erodes the body's defence system, exposing the infected person over time to a range of lung diseases, cancers, fungal infections, wasting, rashes, sores, and other painful and debilitating conditions.

Eventually these AIDS-related illnesses overpower the body's ability to fight back, causing physical – and sometimes mental – ruin and death. There is as yet no cure; the only therapies available are for the treatment of opportunistic infections. One or two new drugs slow down the progression from HIV infection to serious illness; but they are very expensive and have toxic side-effects.

**AIDS: a threat to humankind:** AIDS is one of the most serious threats to human health and life ever faced because:

- For adults the major mode of transmission is sexual, and the urge for physical intimacy is fundamental in all human beings.
- Another important means of transmission is from mother to unborn child, in the womb.
- There is no cure. Prevention is largely dependent on following a self-protective behavioural code, and one which protects others.
- The period between infection with HIV and development of AIDS can last several years. A person may have no knowledge of being infected and can infect others unwittingly.

**Fighting AIDS:** The fight against AIDS at international, national, and local level requires engagement by all groups within society, not only medical scientists and health workers. The fight against AIDS takes many forms:

- Research into all aspects of HIV, to understand its behaviour and develop curative and preventative therapies.
- Spreading correct information about AIDS to dispel stigma, ignorance, and false conceptions, and to guide people, especially young people, to adopt self-protective behaviour.
- Providing care and counsel for those infected by HIV and dying of AIDS, and for family members and partners.
- Ensuring that hospital practices, blood and blood products, and hypodermic needles used in preventive health campaigns are consistently HIV-free.
- Challenging the immense human capacity for denial about the threat of AIDS, and lifting taboos surrounding the discussion of sexually transmitted disease.

horrors of damage and destruction. It is a deserted hut collapsing here, a plot overgrown and uncultivated there, a lonely group of children shivering under a single cotton cloth at night, a tuberculosis patient praying for a peaceful sleep. HIV is an intruder of utmost stealth and secrecy, covering its tracks by the fears it carries in its wake and by the slow pace at which it mounts its assault on the body. Only in the fullness of time is the grim extent of its presence revealed. By then, it is far too late for the many already affected to take cover.

Those involved in the fight on the AIDS frontier of Africa believe that fundamental behaviour change, especially in the generation not yet embarked on a sexual and childbearing career, is the only way to prise the virus away from its deep penetration in the population. With no cure or vaccine in sight and most symptomatic treatment far outside financial range in economically disadvantaged countries, the spread of information about the disease and its swift absorption into new personal codes of sexual and marital relations are the critical weapon. The message to “love carefully” is more urgent than two such simple words can possibly convey.

Human nature has immense capacities for denial. It is easy for those in places and countries not yet at serious risk of personal confrontation with AIDS to go on believing that this is some exotic complaint confined to special populations. The global war against the virus, in which the international public health and caring community is giving its best, is remote from most people's preoccupations. It must not remain so. The AIDS weakling whose short journey in the world was irretrievably marred is as integral a member of the family of mankind as anybody's child.

The World Health Organization (WHO)



estimates that already, 6.5 million people are HIV-infected of which at least two million are women, and that by the year 2000 there will be as many as six million AIDS cases. If, by a miracle, no further transmission of the virus took place, there would still be a mounting caseload of illness and death well into the next century.

As alarming as the sheer numbers is the changing profile of AIDS' epidemiology. The pattern of disease transmission is by no means immutable in any place or population group, currently infected or otherwise. In parts of Asia, where there are still very few cases, the pace at which the virus is moving through different population groups on a predestined path to the family threshold is a cause of extreme concern. And everywhere, in developing and industrialized countries alike, women and children are carrying an increasing share of the burden.

UNICEF has been involved in the fight to protect women and children from AIDS since 1987, both in efforts to prevent its spread and to soften its impact. New ways are now being sought to harness the organization's special mandate for child survival and health and its expertise in programme delivery and social mobilization to the international drive against the calamity.

This publication looks at the special predicament of AIDS-affected women and children in developing countries, at the damage HIV is inflicting on families and communities, and at the urgent need to contain its destructive force against life itself.





## Children and AIDS

### How do children get AIDS?

At the outset of the AIDS pandemic, the threat posed to infants and young children was scarcely perceived, so strong was AIDS' association in the public and professional mind with male homosexual activity and intravenous drug use.

Initial fears concerning AIDS and children centered on risks associated with the use of hypodermic needles and blood transfusions, in immunization campaigns and hospital treatment. The first well-publicized cases of AIDS in children were among haemophiliacs and surgical cases, and came from HIV-contaminated blood. These fears led to a major push for thorough sterilization of medical equipment particularly for immunization purposes, and the introduction of measures to ensure the safety of the blood supply in developing countries. While vigilance in these areas remains a priority in the fight against AIDS, concern for the health of the young child has shifted its main focus elsewhere.

In the mid-1980s, HIV infection started to appear in very young children. It transpired

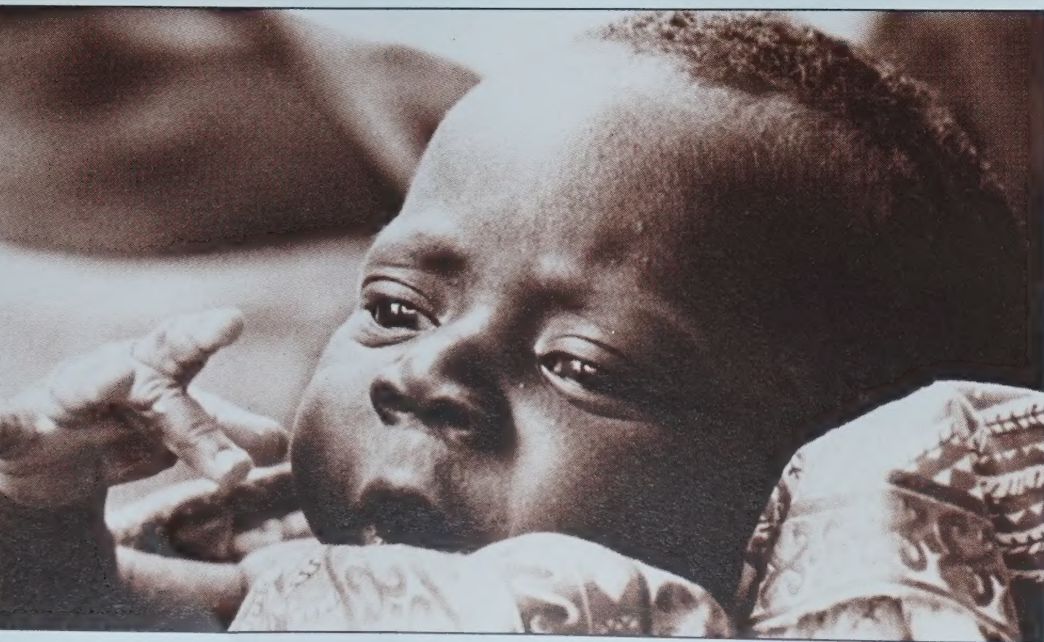
that infected mothers could pass on the virus during pregnancy, usually in the womb, possibly at delivery, and in a very few rare cases in breastmilk. Studies among HIV-infected mothers around the world indicate various rates of HIV in their newborn infants, most falling between 25 and 40 per cent, with what appears to be a higher risk in women whose own HIV infection is far advanced. Experts are now convinced that nearly all HIV infection in small children is perinatal in origin.

Thus the AIDS threat to the young child is intimately associated with HIV infection in women. This is alarming because everywhere in the world, the caseload in women between the ages of 15 and 49 is growing.

In Europe and the USA, children born with HIV infection are mostly the offspring of intravenous drug-users or their partners. In industrialized countries, men with AIDS far outnumber women and the infant with AIDS is still relatively uncommon. But in the developing world, where three-quarters of the two million HIV-infected women reside, it is from the family partnership, often unknowingly on either side, that the typical HIV-infected infant is born. Some may be children of casual relationships, of sexual favour bought and sold. But the vast majority were conceived by parents simply fulfilling the natural human urge for physical intimacy, love and procreation.

WHO estimates that there will be up to six million cases of adult AIDS by year 2000. As the 1990s progress and increasing numbers of HIV-infected women become pregnant, increasing numbers of children will come into the world under sentence of AIDS. In some African and Caribbean countries, 10 per cent of the AIDS caseload is already carried by the under-fives. As new foci of the infection develop, not only in Africa and the Americas

*"Nearly all HIV in small children is perinatal in origin."*





### Patterns of AIDS around the world



The epidemiological patterns of HIV transmission vary in different regions of the world. Three distinct patterns have been identified by WHO.

**Pattern I:** 90% of cases are homosexual males or injecting drug users; overall population prevalence is less than 1% but over 50% in high-risk groups.

**Pattern II:** Heterosexual transmission predominates, with equal numbers of men and women affected; prevalence is over 1%, with 10%-25% in some sexually active urban populations.

**Pattern III:** Relatively few cases reported so far, with initial cases stemming from contacts with AIDS carriers from Pattern I and Pattern II countries.

As the AIDS pandemic emerges, countries and regions can move from one pattern to another, as is happening in Latin America where Pattern I is giving way to Pattern II.

but in Asia as well, the impact on children will escalate.

#### Trying to pin down the numbers

Trying to pin down the precise numbers of children with AIDS is very difficult. Since AIDS is a recent disease, and one frequently hidden, all evidence concerning HIV incidence is based on a small amount of data. Information concerning AIDS in children is the most elusive of all. Many cases in devel-

oping countries are never detected or reported and figures are therefore speculative. Most cases are in large towns, but HIV infection is also spreading in the countryside.

WHO estimates that during the 1980s, 200,000 HIV-infected infants were born worldwide. The numbers are growing: by 1992, 250,000 are likely to have been born in Africa alone. This toll may seem very small compared to the millions with malaria, pneumonia, measles and diarrhoeal disease. But





*"Where mothers and squawling toddlers line up for the monthly clinic, busy MCH staff may not distinguish HIV-related illness."*

from these by far the majority of cases recover, whereas with AIDS, all HIV-infected children can be expected to die an early death. The enormity of the HIV threat lies less in the sensationalism of numbers than in the remorseless outcome of contracting the infection.

In an adult, the AIDS virus can lie dormant in the body for over ten years before manifesting AIDS-associated illness. But should an adult desire to know whether he or she is HIV-infected, this can be positively or negatively confirmed, assuming the test is available and the person has the courage to take it and face the possible outcome. In an infant, the presence of the virus is much more

difficult to detect. Newborn babies of infected women may carry their mother's HIV antibodies until the age of at least 18 months without actually being infected themselves, and most simple HIV tests cannot tell the difference.

#### **The course of AIDS in the small child**

In an adult, the course of AIDS is distinctive. The virus has well-known associations with certain skin, lung and lymphatic conditions, and with the abnormal wasting which has dubbed AIDS "slim disease" in Africa. But in the young child, diagnosing AIDS is much more difficult. The AIDS infant suffers chronic diarrhoea, fevers, loss of appetite, and respiratory infection – all typical ailments of early childhood. So symptoms can be easily misread and often are so.

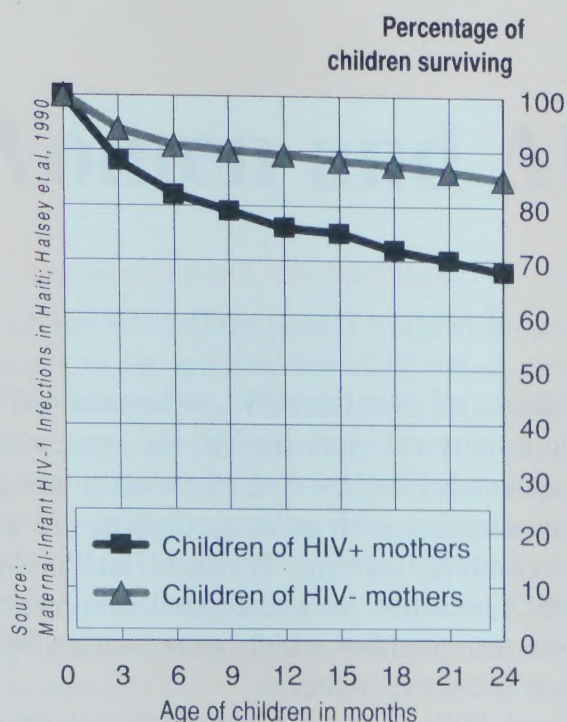
A typical HIV-infected baby begins to suffer related illness at or before six months. Some are unable to absorb nutrients to the point where they not only fail to gain weight but begin to lose it. Mothers in underprivileged communities, especially those unaware of their own HIV infection, may not initially be concerned: temporary failures to grow are not uncommon.

In an African setting, children often succumb to what is described simply as "a sickness" – diagnostic precision is not known, and disease is often attributed to supernatural causes. Given the distance to the health centre and the expense of going there, a rural mother will often try every traditional remedy and wait until her child is seriously ill with a number of symptoms before seeking medical attention. Stigma against AIDS, and fear, also discourage mothers from recognizing, either to themselves or to others, its presence in a member of the family.

In most children the course of AIDS is swift because the small body has not yet had



### Survival rates of children born to HIV-positive and HIV-negative mothers



The children of HIV-infected mothers in Haiti showed higher death rates than the children of uninfected mothers.

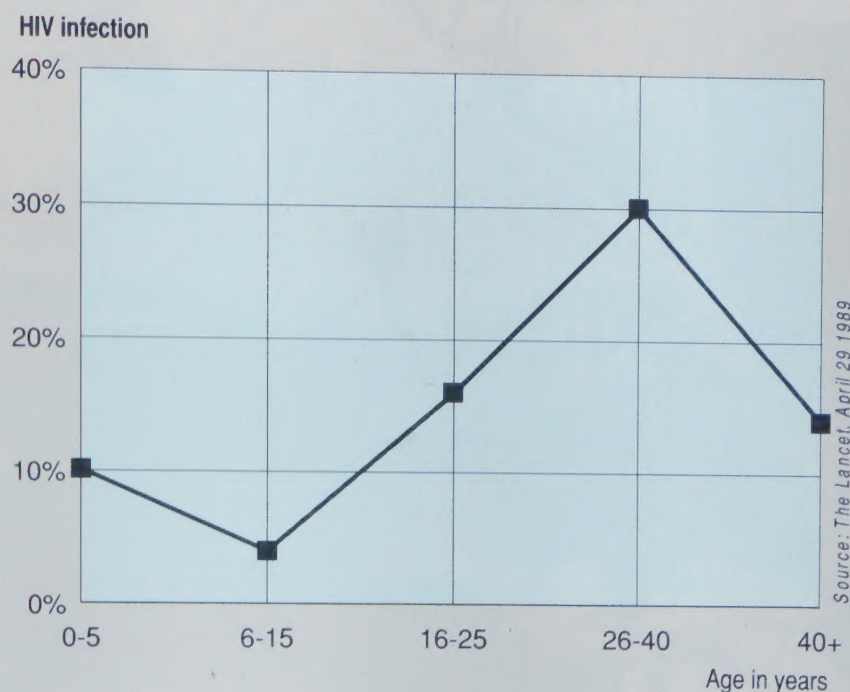
time to build its defences. In Cité Soleil, a poor urban neighbourhood in Haiti, 13 per cent of children of HIV-infected women died before three months of age, 23 per cent before their first birthday. It is currently assumed that, on average, nearly half of HIV-infected children die before age two, and that by the age of five, 80 per cent have perished.

### Caring for the AIDS child

The problem of identifying and treating AIDS in children is particularly acute where maternal and child health (MCH) services are rudimentary. Where lines of mothers with squawling toddlers line up outside the monthly clinic, busy MCH staff may not distinguish HIV-related illness. Nor, in a crowded public setting, may they want to raise the possibility with a mother who apparently has no symptoms of her own. Fatal illness is very hard to discuss at the best of times; extremely difficult when it is sexually-transmitted and surrounded with stigma and taboo.

When efforts to treat a sick child persistently fail, an MCH worker may be forced to

### AIDS in childbearing adults and in children



The AIDS virus is most often found in very young children, who die before age 5, and in adults of childbearing age. Children in the age-group between 5 and 15 years are almost untouched because they have missed perinatal transmission and have not yet become sexually active. (Survey among a sample of urban population, Rwanda.)

draw the correct conclusion. Then she may simply send the child and mother home. Apart from standard treatment for diarrhoea, coughs and fevers, medical science can do little to bring the ailing child relief. At some hospitals, admission of children with suspected AIDS is discouraged; it disrupts the family, is a heavy financial burden and occupies much-needed beds. In rare cases children must be given institutional care because of abandonment.

When nursed at home, the sick child consumes a mother's time and her physical and emotional energy. Whether or not medical treatment is given, a mother must nurse her child and suffer the continuing anguish. That anguish may include the first intimation that she, too, harbours the AIDS virus. If her own health is in decline, her resources for caring are limited. Maternal sickness and death is an additional risk to the health and survival chances of a newborn child in any society, whether HIV-infected or not.

Whatever the prognosis for the HIV-infected child, the experts consider that standard





*"Saving women from HIV infection is the key AIDS child survival strategy."*

vaccinations should be given against immunizable disease, except tuberculosis vaccine (BCG) when a child shows clinical AIDS symptoms. So far, no case of AIDS has been attributed to contaminated immunization equipment. The experts also recommend that HIV-infected mothers continue to breastfeed: in a poor environment the nutritional and immunological benefits far outweigh the risks of HIV transmission.

#### **Impact on child mortality**

During the 1980s, UNICEF helped to generate a concerted attack on deaths in young

children all over the world. A "revolution" in child survival and health was promoted, spearheaded by low-cost, elementary, protective measures such as immunization and oral rehydration therapy. Primary Health Care (PHC) networks were energized everywhere, even in countries which were cutting back their social expenditures.

As AIDS spreads it threatens to undermine these advances. WHO calculates that where one in ten children would be expected to die before age five without AIDS, and where 20 per cent of pregnant women are HIV-infected, the child mortality rate rises by over one-third. Where the proportion of infected pregnant women is as high as one-third, the child mortality rate may rise by over one-half.

A recent UNICEF study has estimated the impact of AIDS on child mortality in 10 Central and East African countries: Burundi, Central African Republic, Congo, Kenya, Malawi, Rwanda, Tanzania, Uganda, Zaire and Zambia. By the end of the century, the death toll from AIDS among the under-fives in these countries alone, if present HIV infection trends continue, is expected to reach up to 2.7 million. The under-five mortality rate, instead of dropping to around 132 deaths per 1,000 live births as earlier projected, is likely to rise, to between 159 and 189 per 1,000.

Since the vast majority of paediatric HIV transmission takes place in the womb, the major means of prevention is to contain the spread of HIV in women. With AIDS, the links binding maternal with child health are absolute: every mother of a doomed infant is also going to die from AIDS. Saving women from HIV infection is the key AIDS child survival strategy.



# Women and AIDS

## Partnerships and HIV infection

Of the 6.5 million people worldwide now thought to be carrying the AIDS virus, two million are women. Their distribution in different parts of the world is very uneven, depending on whether or not the major means of HIV transmission is between heterosexual couples. At least 1.5 million HIV-infected women are to be found in Africa and the Caribbean, where as many women are infected as men.

The AIDS caseload seems to be at its heaviest among women in the prime childbearing years. In the Caribbean, the highest concentration of female infection is between 20 and 34 years old, and similar patterns are reported from Africa. In Uganda, there are more cases of AIDS in women between the ages of 20 and 29 than in all other age-groups combined. The age profile of AIDS tends to be younger in women, with more cases than men in the lower age groups, and fewer than men over age 45.

Although HIV is more common among those who engage in high-risk behaviour and those with many sexual partners, most cases of infection in women in the developing world result from straightforward sexual relations within regular partnerships, usually between an infected husband and wife. This aspect of the course of HIV infection is deadly for it strikes at the heart of family life. Whoever brings the virus into the family, it often makes its first explicit appearance when a newborn child sickens and dies. When the mother's own infection is revealed, she may be expelled from the family home.

The health and life situation of any woman is critical to the health and life chances of her children, not only during pregnancy, childbirth and the early months of life. Beyond this stage, a mother's capacity for



*"The AIDS caseload seems to be at its heaviest among women in the prime childbearing years."*

child care – the time and energy she can devote to her children, the conditions in the home, her material resources, her skills and knowledge – continue to govern a child's passage from childhood to maturity, physically, socially, and emotionally. Whether or not an HIV-infected woman transmits the virus to one or more of her children, her early death from AIDS will have a profound impact on all of them.

## A lack of say in sexual matters

The spread of HIV all over the world has been enhanced by the relaxation of sexual codes. Urban proliferation, the spread of communications, and the loosening of rigid family and social structures has had a profound effect on personal behaviour. Rising rates of



*"For many women, the threat of AIDS begins with a lack of control over their sexual lives."*

adolescent pregnancy and prevalence of sexually-transmitted disease (STD), particularly in the 16 to 24 year-old age group, are causes of alarm to public health officials. This latter trend has special connections to the spread of HIV. A person with a genital sore has a greater risk of contracting the AIDS virus during sexual contact.

For many women in developing countries, the threat of AIDS begins with a lack of control over their sexual lives, or the sexual lives of their husbands outside marriage. In deci-

sions about what takes place sexually between man and wife, women have limited say: such matters are often not discussed.

The subject of contemporary sexual and marital practice the world over is fraught with inhibition and prejudice. But everyone caught up with the AIDS calamity in Africa – health workers, counsellors, teachers, people who have friends and relations dying – points to existing codes of sexual practice as requiring the most urgent attention. There is evidence from Thailand, where the epidemic is far less advanced but is steadily growing, that in Asia too the AIDS virus will use drug abuse and prostitution, the sexual behaviour no-one wants to talk about, as routes into the family fold.

#### **AIDS and maternity**

Even without the new threat posed by HIV, many women in developing countries conceive and bear children in conditions far from ideal. Every year, 500,000 women die from causes related to pregnancy, all but 6,000 of them in the developing world. The heightened risks stem from the thin spread of family planning, ante-natal and maternity services, and women's poor existing state of health.

Since the advent of AIDS, barrier contraception has taken on an important prophylactic role against the spread of HIV. Unfortunately, in many traditional environments women have little opportunity to protect themselves by contraception either from the risk of HIV infection or from unwanted pregnancy. A policy of deliberate family planning using modern contraceptive methods is unusual among couples in most low-income African communities. Nor are condoms widely available or cost-free. Effective use also requires careful use on each relevant occasion and that a partner be informed and co-opera-







tive. Open discussion of sexual activity, between couples and in society, is a pre-requisite for the use of most contraceptives for whatever purpose they are employed.

The rapid rise in HIV infection among women in some locations is a clear indication that too little such discussion is taking place. In every AIDS-affected community, the numbers of pregnant women carrying HIV are growing. A study from Haiti showed a rise from 8.9 per cent in 1986 to 10.3 per cent in 1988. In one city in Eastern Africa the infection rate has shot up from two per cent to over 18 per cent in less than five years.

Generally, rates show marked increases from year to year.

Even where contraception is available, women who know they are HIV-infected do not necessarily avoid pregnancy. Many cultures, and individuals, attach a very high value to childbearing. In many societies, motherhood – especially the bearing of sons – may be the decisive factor in determining a woman's status. In places where it is not uncommon for one child in every four to die before the age of five from other health problems, a one in three risk of bearing an AIDS child may not seem so high. In Haiti, it was found that pregnancy was as common in women who had AIDS or who knew they were HIV-infected as in women who were free of HIV.

#### **Treatment for the woman with AIDS**

Except in the context of maternity, women often have less access to medical services than men. One hospital in East Africa has 14 general surgical beds for women for every 40 beds for men. Women are typically back home in

*"The AIDS virus will use the sexual behaviour no-one wants to talk about as a route into the family fold."*

#### **The rapid rise of HIV in women**

Since AIDS is a recent disease there are as yet few studies over several years showing the spread of HIV in a given population group. The trend in pregnant women is showing that the rise can be rapid.

	1986 %	1987 %	1988 %	1989 %
Blantyre, Malawi	4.2	11.7	–	–
Port-au-Prince, Haiti	8.8	9.9	10.5	–
Bujumbura, Burundi	16.0	–	–	20.0
Kampala, Uganda	14.0	–	–	24.0
Kigali, Rwanda	18.1	–	–	30.0
Ivory Coast	–	3.0	6.1	–

Sources: J. Wilson Carswell, paper for UNICEF, April 1990; abstracts from International AIDS Conferences; UNICEF Annual Reports



# AIDS, women and children: the facts

## AIDS in women

The crucible of AIDS as a family tragedy is the HIV-infected woman. Of the 6.5 million HIV-infected people in the world, two million are women of childbearing age.

The vast majority of women with HIV and AIDS are in the developing world where the financial and infrastructural resources to deal with the destructive force on family life are weakest.

A woman with AIDS not only lives under her own sentence of death but has to endure the damage to her childbearing and nurturing role. She has a 25% to 40% chance of passing on HIV to a child in the womb or at birth.

Africa contains almost 1.5 million HIV-infected women. In some countries, between 10% and 30% of urban women are infected. UNICEF calculates roughly that each woman dying of AIDS will leave behind an average of two children. Since she is the key provider of food, clothing, and household utilities for all her children, a mother's death has profound social and economic consequences for her orphans, and for her husband if he survives.

## AIDS in children

Children born already infected by the AIDS virus have a 25% chance of dying before age one, an 80% chance of dying before age five (WHO estimates). Although it is difficult to make a conclusive diagnosis of HIV infection in the first few months of life, children born to HIV-infected mothers consistently show higher death rates than those born to uninfected mothers.

At or before six months, the AIDS infant's growth begins to falter or regress because nutrients cannot be absorbed efficiently.

The child becomes unusually prone to childhood ailments - diarrhoeal disease and acute respiratory infection - but has less capacity to fight back or respond to treatment.

## The global toll of AIDS in women

Two million women of childbearing age are now HIV-infected. Most are married women living in unexceptional family circumstances, meeting conjugal needs and expectations. Among prostitutes and IV-drug users, the rate of infection is as high as 50%.

### Proportion of women who are HIV-infected

There are 1,250 million women in the world aged between 15 and 49 years, of whom an average of 160 per 100,000 are HIV-infected. The proportions infected vary dramatically between regions.

### Number of HIV-infected women per 100,000

140	North America
200	South America/Caribbean
70	Western Europe
5	Eastern Europe
20	North Africa / Middle East
1,500	Sub-Saharan Africa
5	Asia
70	Oceania

### Estimated numbers of HIV-infected women

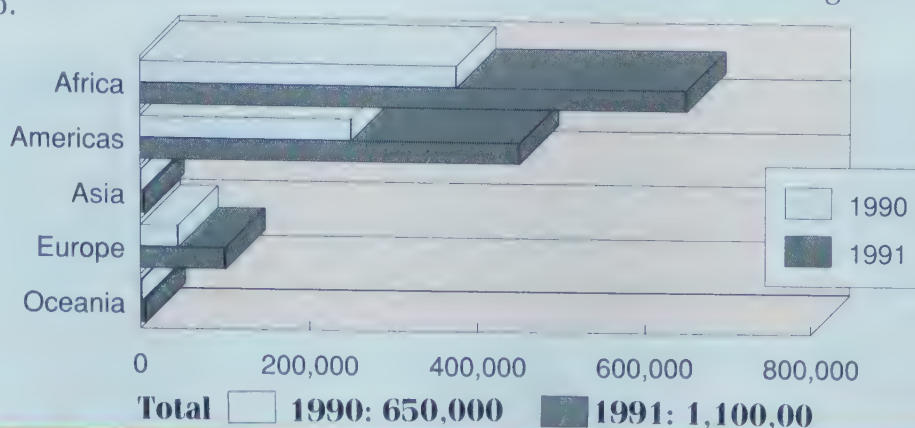
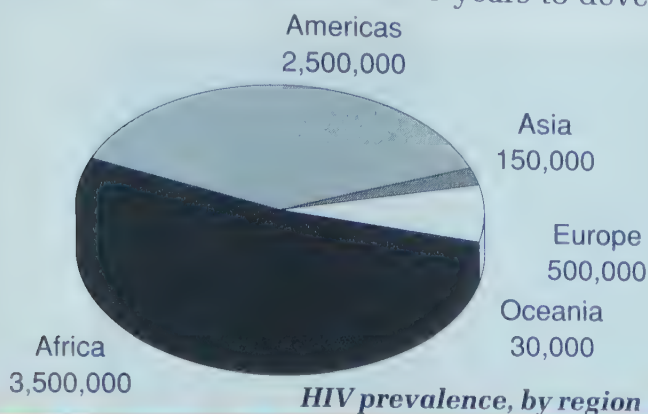


Source: WHO



## HIV and the growing AIDS caseload

6.5 million people throughout the world are now infected with HIV, half in Africa, one third in the Americas, the rest elsewhere. WHO estimate that ten times as many people have contracted HIV as those suffering from AIDS, which can take over 10 years to develop.



## The upcoming devastation of family life in Africa

In ten Central and East African countries, recent gains in child survival will almost certainly be wiped out by the impending tragedy of deaths in women and the under-fives during the 1990s.

The study included the following ten countries:

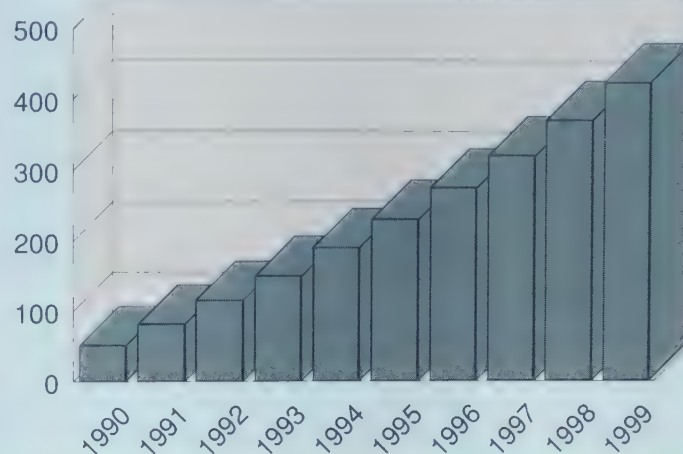
- Burundi
- Central African Republic
- Kenya
- Malawi
- Peoples Republic of the Congo
- Rwanda
- Tanzania
- Uganda
- Zaire
- Zambia



### Projected number of AIDS orphans

During the 1990s, up to 5.5 million children under 15 will lose their mothers to AIDS.

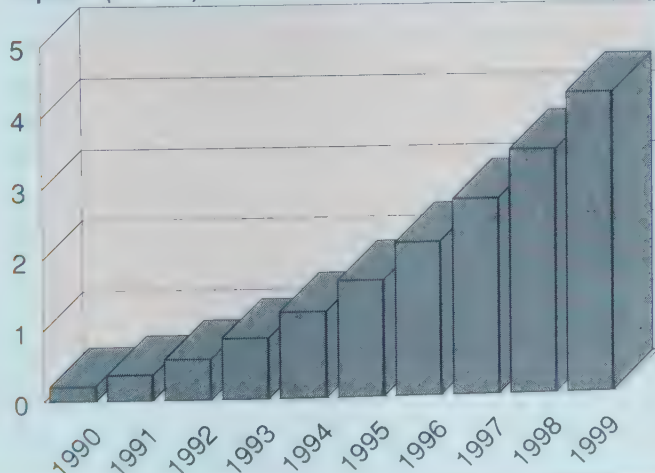
Women aged 15-49 (000s)



### Projected AIDS deaths in women aged 15-49

During the 1990s, up to 2.9 million women will die of AIDS.

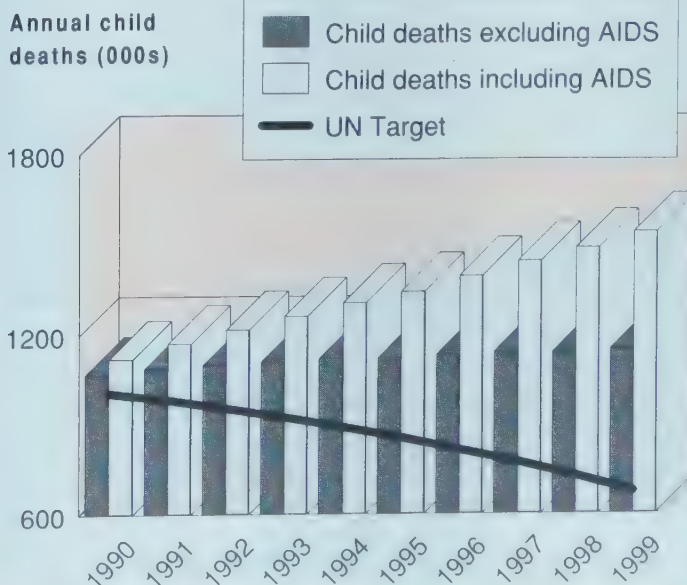
Orphans (millions)



### Projected AIDS deaths in children under five

During the 1990s, up to 2.7 million children will die from AIDS.

Annual child deaths (000s)





*"The AIDS mother must try to ensure that the future of her children will not be ruined as a legacy of her impending death."*



the village, practising cultivation and managing the household. Men more frequently go off to gain a foothold in the modern economy, finding jobs in population centres where facilities such as hospitals are based.

The spread of HIV in women has not affected the way medical treatment is loaded in favour of men. In Uganda, studies have shown that women AIDS patients are much less likely to receive medical care than men even when they are similarly affected.

Care offered to a woman with AIDS needs to take into account many more aspects than the medical. Most women must count on a female relative – mother, sister, elder daughter, or co-wife – not only to nurse her but to help look after the children. As her strength fades, she also needs economic and domestic

support: house maintenance, help with fetching water and fuel, and with cultivation and storage of the family food.

Finally, the woman with AIDS carries a heavy psychological burden. She is often unfairly blamed for bringing the affliction and its accompanying stigma into the family. During her own decline she has to cope with the knowledge that her death will damage the chances in life of her surviving children. In many households, children depend on their mothers not only for nurture but for daily food, clothing, school fees and expenses. Somehow the mother with AIDS must try to ensure that her dependent children will be cared for, and that their schooling and future prospects will not be ruined as a legacy of her impending death.



# AIDS and family life

## AIDS orphans

During the 1990s, up to three million women are expected to die from AIDS in Central and East Africa alone, with devastating social and economic impact on their families. The number of AIDS orphans is already beginning to affect family life in the places where the virus is most rampant. In orphanages in Port-au-Prince, Haiti, over half of children under 18 months are HIV-infected. UNICEF calculates that in ten countries of East and Central Africa, if present HIV infection trends continue, up to 5.5 million children under the age of 15 will be orphaned by the year 2000.

These figures seem startling, almost unbelievable. But in some places, the number of AIDS orphans is already very high. In Rakai in southern Uganda, a recent Save the Children Fund survey puts at over 24,500 the number of parentless children under the age of 18 years old, 12.5 per cent of the age-group. For two-thirds of these children, the bereavement took place within the past four years when the mortality rate from serious illness of adults in the prime of life suddenly shot up, with AIDS as the only possible explanation.

In Rakai and neighbouring Masaka districts, over 20 per cent of adults are HIV-infected. Funerals occur almost daily in many villages. Farming plots are visibly overgrown and untended; mud and lath houses are crumbling, no longer in use because the owners have died. Most of the orphaned children of AIDS have been taken in by relatives and grandparents in the time-honoured way of the African extended family. But resources are severely over-stretched. In nearby Bukoba district in Tanzania, there are many similarly bereft children dependent on aged relatives.

Grandmothers who would normally count upon sons to provide for their old age are



instead burying their adult offspring and caring for seven, ten, 13 parentless children with no means and little strength to do so. Young widows now raise not only their own children without conjugal support, but those of their late husbands' dead co-wives, facing dubious health and survival prospects of their own. The problem of how the extended family can continue to provide food, clothing, and educational expenses, not to mention love and affection, for all the extra children it has to absorb may soon become the most important social challenge in AIDS-affected Africa.

In a geographical area where one-fifth of the able-bodied adults are destined to die within the next few years, the proportion of young and old to the economically productive members of society will grow rapidly. In rural areas in many non-industrialized societies, a strong physique represents the basic unit of capital in the economic system and is a prerequisite of meeting most day-to-day survival needs. The overload of non-productive people on the rest is beginning to produce stresses for which no traditional coping mechanism exists.

Where farming based on manual labour is the main economic activity, elderly people and those who are in an advanced stage of

*"Children orphaned by AIDS have been taken in by relatives; but the extended family's resources are severely over-stretched."*



*AIDS orphans in Rakai, Uganda, come together to receive a monthly bar of soap and other extras under a mission hospital outreach programme.*



sickness have insufficient strength for the strenuous digging needed for planting. In Rakai and Masaka, not only is land under-utilized, but the standards of cultivation have declined, there is a higher level of pest infestation, and since the AIDS epidemic took hold, families have become more vulnerable to crop failure and food shortage. Those with many children and few adults are particularly prone to malnutrition.

Many AIDS-affected families cannot find the wherewithal to keep children in school. Even where fees are paid, by government subsidy or humanitarian assistance, youngsters' labour may be needed for cultivation and domestic duties. Some families are now headed by children of 14 and 15 years, who have taken on the role of family providers by farming and casual employment. Their rights to the land owned or let by their parents are jeopardized by a father's early death, as are the rights of a widow to cultivate her dead husband's plot.

Institutionalized care in orphanages for children bereaved by AIDS is not the optimal course of action. Such institutions could not be supported in adequate numbers in the African countries affected. Nor would an upbringing far removed from the normal

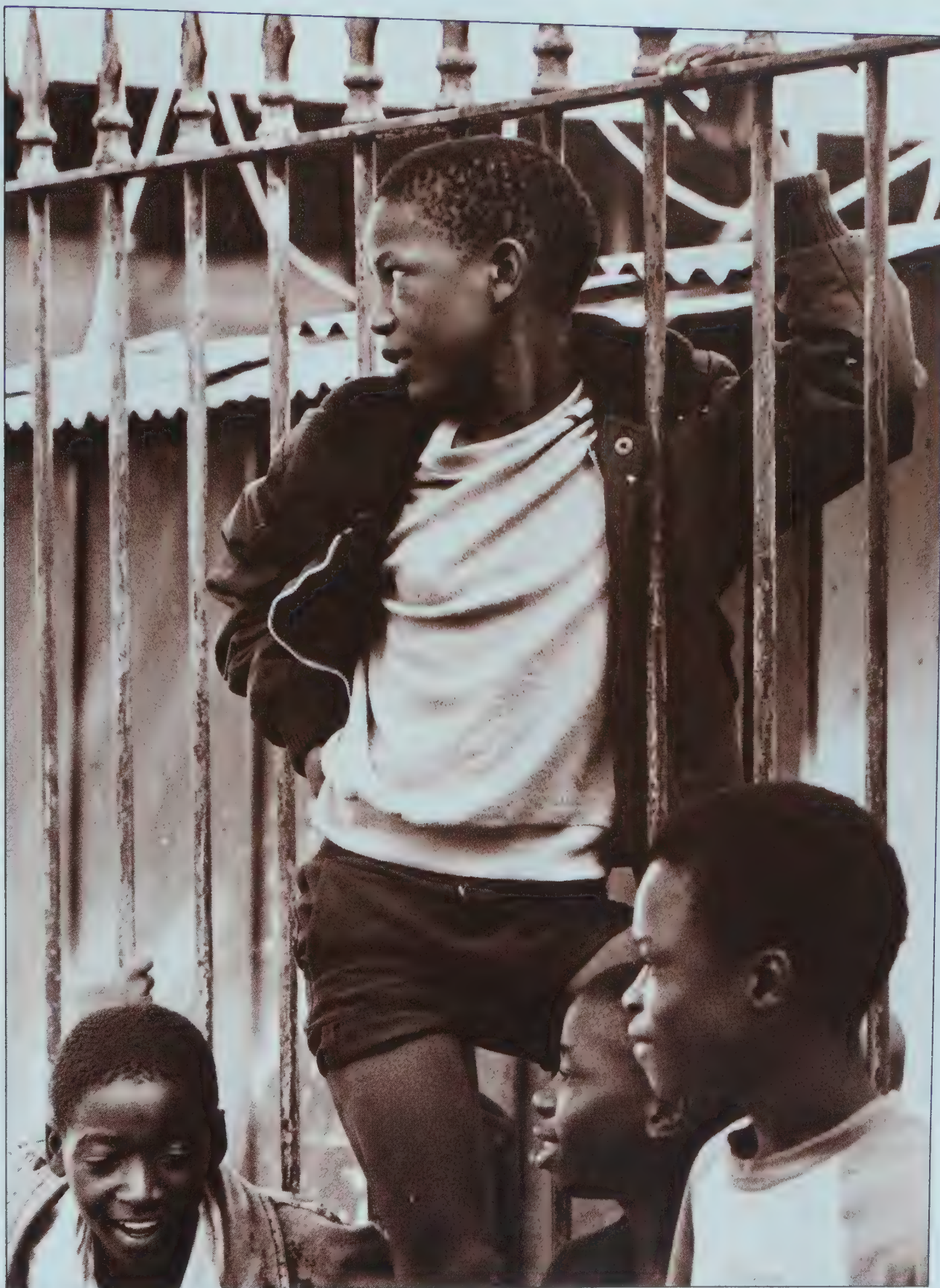
course of life suitably equip these children for their future place in society. Urgent attention is now being given to how to bolster existing extended family networks.

### **Children on the streets**

Parental loss in urban areas presents other hazards to AIDS-orphaned children. In the poorer neighbourhoods of many Third World cities, family bonds are already under duress. The exigencies of urban life, where income-earning opportunities rarely match up to the higher costs of living, overwhelm many families. Hardship cannot be cushioned by the networks of family responsibility typical in rural settings, and many women and children are forced into menial, often exploitative situations as a means of family survival.

Worldwide, UNICEF estimates that 30 million children spend most of their time on the streets, earning a little money here and there by vending newspapers, shining shoes, minding cars, washing windshields. Of these, around 10 million are to all intents "abandoned", have lost or severed links with their parental homes. As increasing numbers of city children are orphaned by AIDS, and surviving relatives cannot cope, many are bound to join their ranks.





*"City children orphaned by AIDS may join the ranks of street children, themselves prime targets for HIV infection."*

These youngsters are themselves prime targets for HIV infection. Their life-style often places them on the wrong side of any law designed to protect the health and well-being of minors. Emotionally vulnerable and economically hard-up, such children are easily drawn into selling sexual favours. In many parts of the world there are child prostitutes

of eight, nine, and ten years old whose prospects of protection against AIDS are negligible. Seven per cent of street boys aged 6–14 in Khartoum are HIV-infected. In Sao Paulo, Brazil, nine per cent of children tested in state institutions were HIV-positive, mostly from sharing needles during intravenous drug abuse.



## The impact on services



The tragedy of AIDS' impact on women and children is compounded by the fact that HIV has begun its penetration of the developing world at a time when many governments have been forced to cut social services as part of economic adjustment policies. In almost all African countries, debt and low prices for export commodities mean that there is not enough money to run regular services properly, let alone expand to meet the threat of AIDS effectively.

The impact of HIV infection is felt most heavily by the health services. Many AIDS-affected areas, particularly those far from the capital, were under-served by hospitals and health services before HIV invaded. Caring for the HIV-infected as outpatients and on medical wards is adding an extra strain, as are efforts to enforce infection control procedures and to screen the blood supply.

In Africa, government spending on health care ranges from \$1 to \$10 per person per year; \$1 is roughly the cost of one use of the ELISA test to discover whether a blood sample contains HIV. The cost of health care for each patient with AIDS in Zaire and Tanzania is estimated at between \$100 and \$1,500 - a negligible sum compared to the \$50,000 spent on each child with AIDS in the state of New York during 1989, but an almost impossibly heavy financial burden in Africa.

Thus, the costs of the elaborate diagnostic tests and therapies for opportunistic infections common to AIDS treatment in the industrialized world, let alone the use of drugs such as AZT for slowing the progress of HIV infection, are far beyond the reach of health budgets in developing countries. Medicinal care for AIDS is limited to antibiotics for lung infections, ointment for rashes, oral rehydration therapy for diarrhoeal disease and other basic remedies. Some of these needs are being



met through programmes for essential drugs in which both WHO and UNICEF are co-operating.

Inevitably, as the caseload of HIV-related illness grows, the time, energy and resources of medical facilities and staff will become increasingly absorbed. Hospitals in AIDS-affected areas show a marked rise in bed occupancy. Tuberculosis is making a come-back among those with weakened immune systems. In Chikankata hospital, Zambia, nearly half the TB patients are HIV-infected, and these cases spent 61 days in hospital on average, compared to 17 days for AIDS patients without TB. This pressure is bound to have an effect on the performance of other services, including MCH. Medical staff are occupationally vulnerable to HIV infection, as well as being vulnerable from sexual transmission. In East and Central Africa, hospitals, schools, and administrative services are losing valuable trained personnel to AIDS.

### **The move towards community care**

The lack of capacity within government services and the very special range of medical, psychological, and practical care needed by those affected by AIDS has been in some measure compensated by the response of non-governmental organizations (NGOs). NGOs such as The AIDS Support Organization (TASO), Uganda, and the Society for Women and AIDS in Africa (SWAA), have been formed in response to AIDS. Others, notably mission hospitals, are pioneering programmes of home-based care supported by mobile teams. These programmes are, wherever practicable, offered technical and financial support by the international public health community, and some of their features are being incorporated into AIDS prevention and control strategies promoted by WHO and UNICEF.

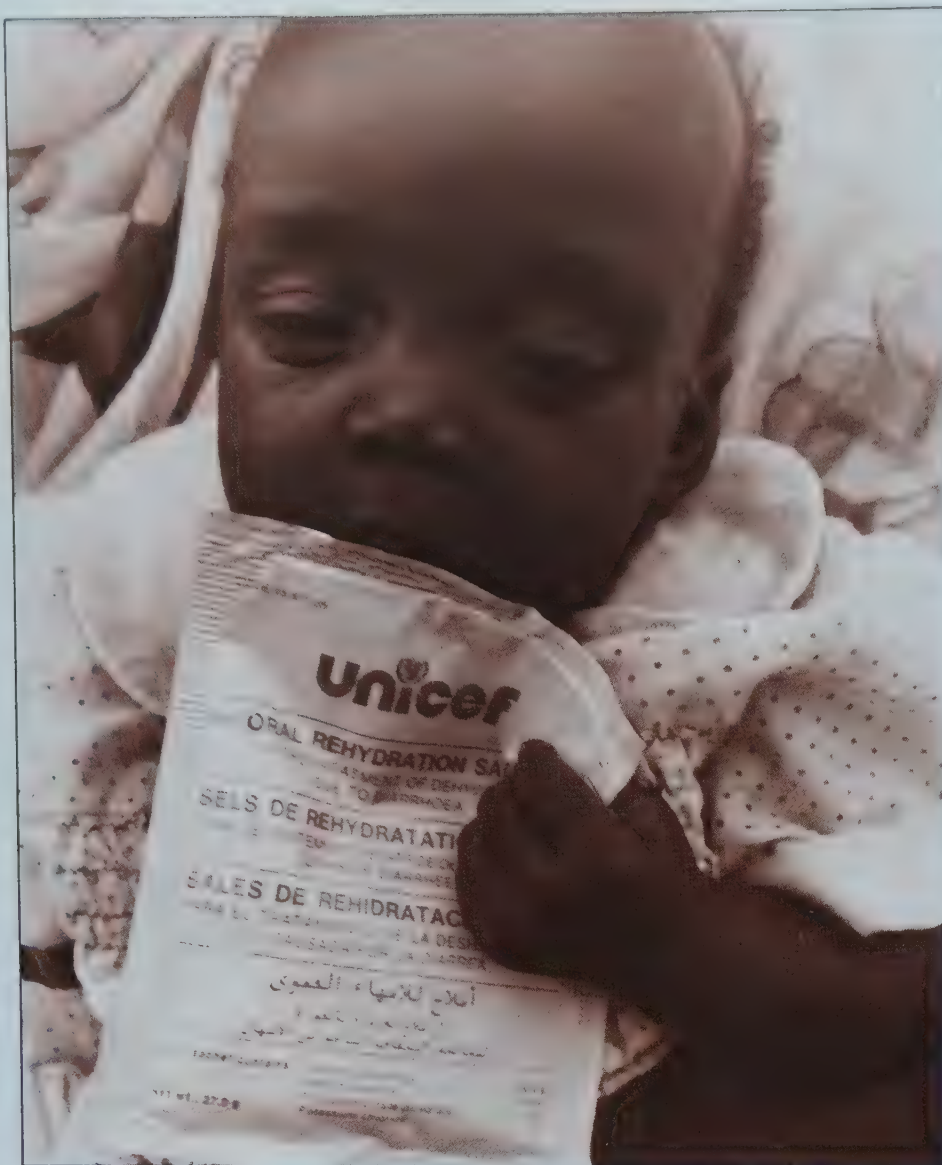
The close contact enjoyed by local, voluntary networks with individual AIDS sufferers and their families is a key ingredient of AIDS management, since by its nature this is not a condition which can be met with mass response in a public setting. Many NGO initiatives combine patient contact, counselling, care, support to the bereaved, and advocacy of self-protective behaviour, as mutually supportive ingredients; UNICEF is working actively with several such programmes. However, no service of this kind currently exists which can do more than tackle a small proportion of cases. Many AIDS patients are hidden away, afraid to come forward. The challenge is to find ways of boosting the service infrastructure to find and cater to many more of them.

Volunteers and professionals working in all service sectors need orientation concerning the nature of the AIDS virus. Those dealing with AIDS patients and others affected need

*"By its nature, AIDS is not a condition which can be met with mass response in a public setting."*







*Diarrhoea occurs two to seven times more often in the HIV-infected child, and oral rehydration is not as effective.*

training in counselling and caring techniques. TASO in Uganda trains and employs as counsellors suitable candidates from among its own clients. Their philosophy is to "live positively with AIDS" and to prolong life by self-care. This innovative programme runs day centres for patients offering comfort, counselling, and income-generating, and is an inspiration to many others.

#### **AIDS and child survival programmes**

AIDS in children represents a threat to existing child survival programmes, both because of its effect on child morbidity and mortality and its potential for diverting human and financial resources away from standard protection of child health. There is also a need to reassure mothers that immunization poses virtually no HIV threat to their children, and that all child survival and health protective measures they have been

taught during the past few years are as valid as before AIDS crossed their horizon.

Experience has shown that it takes not only a thorough presentation of correct information about HIV and AIDS to offset the effect of rumour and misunderstanding, but its constant reaffirmation. In campaigns to control AIDS, as in any campaign directed at changing human behaviour, there is a wide gulf between circulating information and achieving widespread behaviour change. Beaming messages through regular media and communications channels is important, but it is not enough. The messages and their urgency has to be reiterated in the community by leaders, elders, priests and peers, before pressure to change becomes effective.

The Primary Health Care (PHC) structure is an important route for health education and counselling programmes. In this context, the threat to child survival posed by HIV may even have its positive side. Since the easiest place to reach women and children is in the ante-natal clinic, maternity ward, or MCH session, AIDS demands a further effort to vitalize PHC services. The PHC strategy for outreach into the community via the community-based worker should be harnessed to the need to help families fearful and isolated by their AIDS predicament.

A more sensitive form of social mobilization is needed for AIDS prevention programmes in the community compared to that used for more conventional child survival interventions. AIDS can summon stigmatizing, negative behaviours, but it can also arouse a spirit of caring and mutual support which is helping to soften the worst of the human and social devastation.

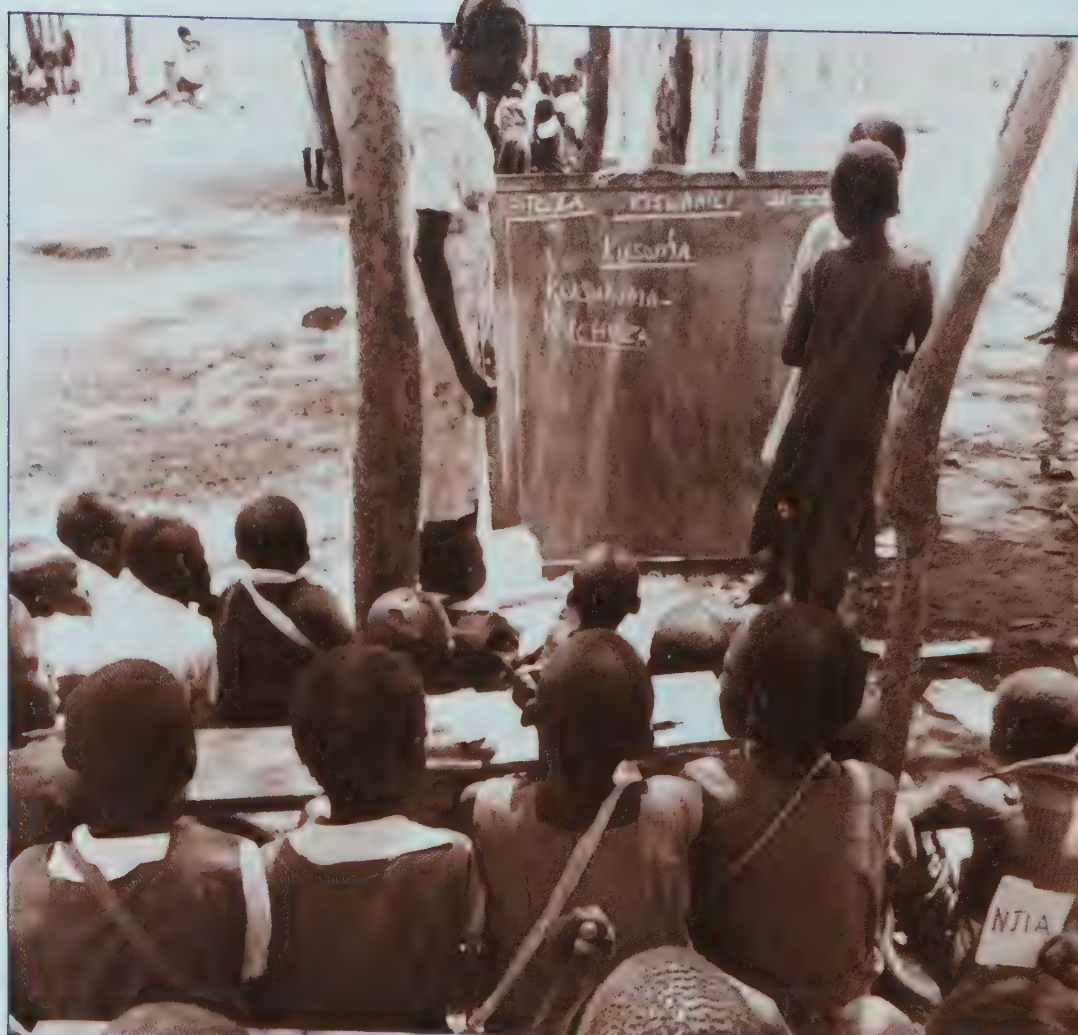


# UNICEF and the response to AIDS

Since the mid-1980s when the alarming impact of AIDS on children, women and family life began to emerge, UNICEF has actively supported the fight against HIV infection. During 1990, UNICEF plans to spend over \$6 million on special AIDS projects in Africa, mostly in East and Central Africa; and nearly \$2 million on global projects and projects in other regions. UNICEF co-operates closely with the WHO (World Health Organization) Global Programme on AIDS, which provides leadership and an umbrella for all AIDS prevention and control activity within the United Nations system. All programmes supported by UNICEF adhere to WHO's Global AIDS Strategy.

UNICEF, along with other organizations fighting AIDS, is determined that the gravity of the AIDS pandemic should not be a cause for demoralization. WHO's Global Programme on AIDS is optimistic that concerted global, regional and national efforts to contain the spread of HIV can prevent millions of people becoming infected, and that every reinforcement of these efforts helps save increasing numbers of women's and children's lives. The Global AIDS Strategy - which is constantly under review - therefore concentrates on three objectives: preventing HIV transmission by any and every route; reducing the personal and social impact of HIV and AIDS; and synchronization of all national and international initiatives to stem HIV infection.

UNICEF's contribution to the WHO-led worldwide effort is designed to help meet the first two objectives of the Global AIDS Strategy. A programme and policy strategy for AIDS was adopted at the UNICEF Executive Board in 1988 (E/ICEF/1088/13 decision 1988/7.1). The strategy sets an urgent time frame for action, respects individual countries' needs, and is concentrated in fields

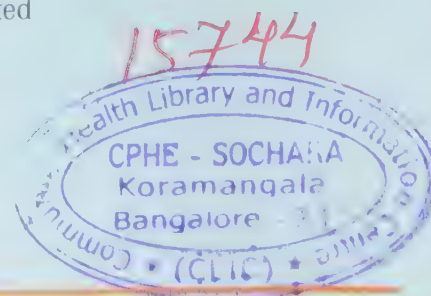


where UNICEF has proven competence. Initiatives are developed as a part of existing country programmes, within which support is given to specific AIDS prevention programmes and to bolstering services so that they can help combat AIDS.

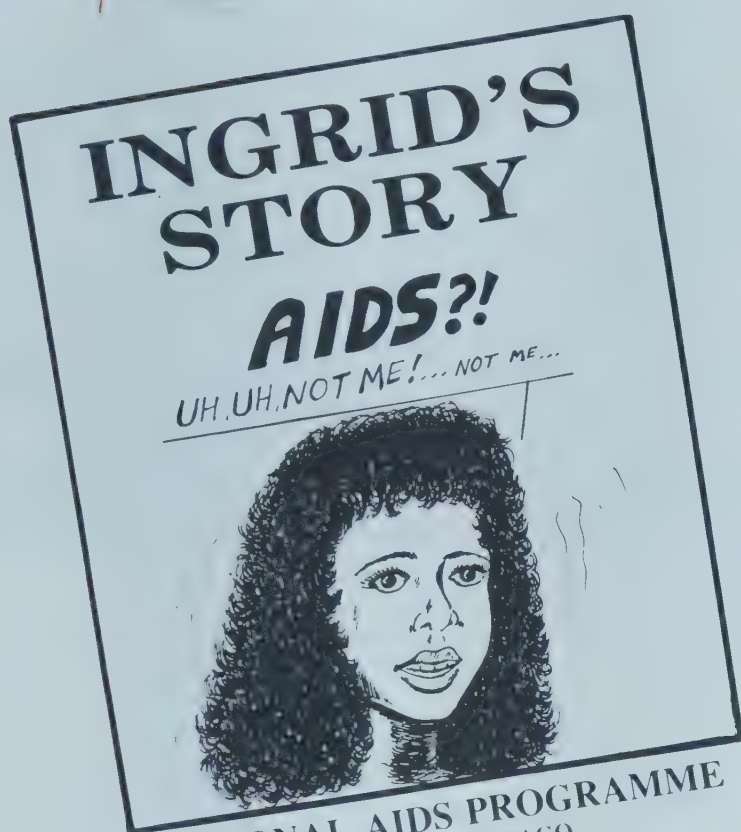
*"Young people must be taught about HIV before they become sexually active."*

## UNICEF's support takes several forms:

- AIDS prevention education activities, through health education, school curricula, and other outlets, to reach women and children at risk;
- orientation and training for those likely to come into contact with AIDS patients or their relatives;
- advocacy, towards governments, donors, NGOs, and the general public, to raise awareness and mobilize resources;
- co-operation with NGOs directly involved in caring for those with AIDS or affected by it;
- expansion of PHC networks and child survival initiatives, including extra attention to sterilization of medical equipment;
- exchange of scientific and technical





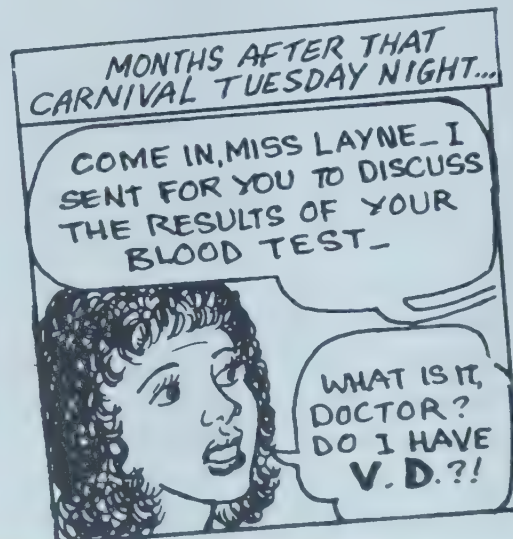


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### Advocacy and behaviour change

UNICEF has supported a wide range of information activities in AIDS-affected countries in the effort to influence young people to adopt self-protective behaviour. Clockwise: (1) "I am an AIDS virus" from a special issue of Pied Crow magazine, Kenya; (2) "AIDS kills: It is mostly spread through sex"; from a set of wall charts for use by health educators, Uganda; (3) "Ingrid's Story", a comic strip book for young adults in Trinidad and Tobago.





information to promote effective programming through funding conferences, workshops and study tours.

### **UNICEF and AIDS prevention**

During the 1980s, involvement with campaigns for child survival has endowed UNICEF with unique expertise in social advocacy. By working with the media and by extensive networking, UNICEF has helped mobilize a range of interest groups - political, occupational, educational, intellectual, religious, humanitarian, sports and entertainment - on behalf of child health. UNICEF is now bringing this expertise to the task of AIDS prevention.

The importance of awareness-building to arm people against AIDS cannot be overstated, both in countries where the virus is already well-established and in those where its threat is yet to be widely felt. In the face of human nature's capacity for denial, it is extremely difficult to penetrate the barriers deep in people's consciousness about the threat of AIDS to their own health and lives and to those of their loved ones. Social mobilization against the spread of HIV infection therefore depends on activating against AIDS all those already committed to working for women's and children's health.

In a number of countries, UNICEF has helped to develop information and education materials about AIDS - posters, pamphlets, cartoon strips, videos, radio spots - for use with a wide range of audiences.

#### **Target: the young**

A key audience UNICEF is especially anxious to reach is today's young people. Those in their early teens must be taught about HIV before they become sexually active.

The subject of sex education in the class-

room is fraught with controversy and some HIV-affected countries have not yet resolved the difficulties of its introduction. Uganda, however, with support from UNICEF, has led the way with a total revision of the science curriculum in primary and secondary schools. Teachers have been trained in a new syllabus which includes health education and AIDS prevention, and textbooks, classroom materials, and extra-curricular activities have been developed.

The Uganda schools programme is regarded as a model for other countries in East and Central Africa also wishing to instill at an early age the importance of "loving carefully". Rwanda and Burundi, with UNICEF co-operation, are placing a high priority on school education, and in Asia, UNICEF is assisting Thailand with a similar programme.

Schools, youth clubs, and other environments in which young people can be reached with messages about AIDS prevention are a natural UNICEF target in a number of countries. In the Caribbean, the high rate of school-girl pregnancies and STDs in teenagers reinforce a picture of urgent AIDS risk among adolescents, which UNICEF is helping to tackle.

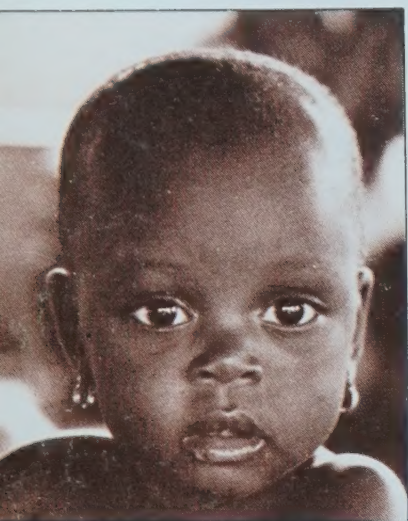
#### **Target: women of childbearing age**

Much of the AIDS education effort has been directed at all women of childbearing age (15 to 49), both through countries' primary health care networks and through regular communications outlets. In Tanzania, UNICEF has held advocacy workshops for women leaders, teachers, and the mass media to improve the level of coverage and accuracy of information transmitted about AIDS. In Zambia, a group of women at high risk is being targeted within an ongoing programme for control of STDs.

In a number of countries, for example in

*"The message to 'love carefully' is more urgent than two such simple words can possibly convey"*





Kenya, Benin, Congo, and Ivory Coast, UNICEF has been actively involved in the preparation of manuals and brochures for the training of health workers in AIDS prevention. In Uganda, a network of assistant district health educators has been set up to co-ordinate AIDS education through church congregations, women's groups, and village committees.

There are already some indications that behaviour change has begun to take place. Some hospitals are beginning to note a drop in sexually-transmitted disease, which is the first encouraging sign. But all the experts agree that there is a long way to go before change is sufficiently radical to make a major impression on the rate of infection.

#### **Support for families, especially orphans**

Despite effective prevention efforts, millions of people already HIV-infected are bound to develop AIDS in the coming years. The impact on families and communities of the loss of a high proportion of key economic providers to AIDS is of growing concern. UNICEF and other organizations interested in children's well-being are now urgently examining how to care for the growing number of AIDS orphans. The challenge is to find ways of helping them economically, socially, and psychologically without distancing them from the normal context of their lives.

In Uganda, where the problem of AIDS orphans is well advanced, UNICEF supports an association of NGOs set up to co-ordinate their own exploratory, research, and practical initiatives to ease the burden of AIDS on family life. This association will develop joint strategies, pool information and provide a channel for resources.

UNICEF will also participate in national and local studies to determine the nature and

magnitude of the problems concerning children whose parents have been lost to AIDS. Its most important contribution will be to help guide governments and NGOs to the most effective programme models, drawing on more than 40 years of experience with programmes for children and families stricken by war, famine, and other emergencies.

#### **Priorities until year 2000**

Over the coming decade UNICEF's main priority within AIDS prevention will continue to be to spread information among key audiences, by offering technical and material support to government ministries, NGOs, and all kinds of social and community groups undertaking AIDS-related programmes.

UNICEF will continue to participate in the international fora where the latest scientific research into AIDS and policy and programming issues are discussed, and provide financial support for such activities where appropriate. These and other opportunities will be used to highlight the predicament of HIV-affected children and women and to reinforce partnerships with key organizations within the UN system, with donors, governments, and with programming and fund-raising NGOs.

The infant with AIDS, whose hurting-somewhere expression, whose aches and fevers can never fully be soothed except in death, must not be allowed to haunt the conscience of humankind. Women, their potential mothers, must be enabled - by information and in other ways - to protect themselves from HIV infection, for their own sake and that of every member of their families. To this effort, internationally, nationally, and in towns and villages in underprivileged parts of the world, UNICEF is fully committed.





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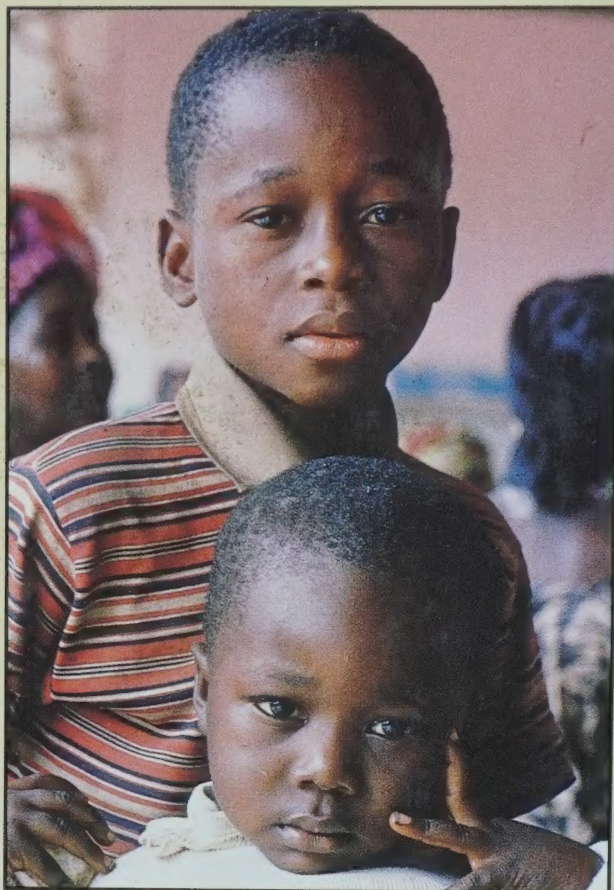
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